### Consumers

**Table of Contents** 

44	Introduction	
44	A personal story of "The Document Game"	
45	You deserve constant access to your personal health information	
47	Helps healthy people stay healthy	
47	Problems with the paper-based system	
48	Electronic medical records, interoperability, and the difference between the two	
48	If paper has so many drawbacks, what is the alternative?	
49	Benefits: Moral, intellectual, and practical	
50	Convenience	
50	You can have constant access to your own information	
50	High-touch and low-touch	
51	Less time filling out forms	
51	Easier contact with your doctor means improved personal and family care	
53	Empowering Patients and Improving Care	
53	Continuity of care	
53	Fewer errors and less wasted time	
54	Both doctors and patients are better informed	
54	Better management of chronic conditions	
54	Electronic prescribing (e-prescribing)	
55	Improved care for expectant mothers and their unborn babies	
55	Makes personalized care possible as future medical advances warrant	
56	Confidentiality, Privacy, and Security	
56	The power of technology to create trust	
57	Why Americans (and the world) have so readily adopted technology	
58	People are growing more comfortable with using technology for healthcare	
59	The good news: Prevention and confidentiality are attainable goals	
61	Individuals want access to and control of their own records	
62	Confidentiality: The core of the doctor-patient relationship	
63	Health Issues for Individual Communities	
63	Access for everyone, including the poor and indigent	
63	Better care in community health centers	
64	Issues in rural areas	
66	Tracking disease and nationwide medical concerns	
66	Military	
66	Veterans	
67	Reducing Medical Errors While Saving Patients' Time and Money	
67	The bottom line	
67	The scope of the problem: By the numbers	
68	Relative risk of healthcare	
69	The financial costs	
69	Financial advantages for patients	
70	Reduce duplication of tests	
70	Dramatically reduce drug interactions	
		Consumers

# Consumers

"A patient-centered system absolutely demands an electronic health record.

To empower wired consumers with information, choice, and control, we need to harness the explosive power of information technology."

Senate Majority Leader Bill Frist

### Introduction

### A personal story of "The Document Game"

Ashley Shaff was born with a chromosomal abnormality that has caused lifelong problems with her eyes, ears, and heart, and contributed to developmental delays, sleep apnea, lung disease, and a host of other conditions. Peggy Frank, Ashley's mother, has had to take personal charge of Ashley's medical records to ensure that complete and timely information reaches doctors and providers caring for Ashley. The sustained effort has been wrenching. Below is an excerpt from Peggy's testimony before the Commission.

[My daughter] Ashley has been seen by one dozen medical facilities, spanning 3,000 miles—literally coast-to-coast. She has had approximately 35 hospitalizations. She has been seen by [at least 36 medical specialists and therapists].... I have had to be ... a "connector," literally running interference between the various physicians and health care facilities to ensure that Ashley's medical records physically get from place to place ... in a timely manner, often under extreme emotional conditions.

Trust me, playing "the document game" is disturbing, especially at times of considerable duress.

The same holds true for ... asking endless medical history questions [that have been asked and recorded by others many times before, but rarely shared with other doctors]. They ask everything that has happened during her entire life and seek great detail on absolutely every single medical procedure, hospitalization, etc., that has occurred over the span of Ashley's life.

I cannot tell you how many times I was reduced to tears.

I remember in Northern California sitting at Ashley's post-operative bedside, crying as I was trying to provide the medical history. I was just told, not minutes before, that she was terminally ill and had about five months to five years to live. This is wrong. It is unkind, and perhaps even a medical mistake waiting to happen. What if I make a mistake, an error or an omission, that has a grave impact on her care, then or in the future?

There is a lot of talk about reducing medical costs by increasing patient safety. Where does having a medical record, easily accessible, fit into this picture?

I believe it to be pivotal.1

### You deserve constant access to your personal health information

Your personal medical information helps guide your medical treatment, but sometimes your complete information is hard to come by.

Parts of the data may be easy to get, usually because you are standing in the office of the doctor who stores that record in the first place, or you are seeing a doctor who works in the same medical practice. Other parts of the information may be much less readily available, because separate information is stored in different doctors' offices, hospitals, and labs. This lack of connection—lack of "interoperability"—among people and among sources of information can result in bad diagnoses, duplicate testing, conflicts in prescriptions, wasted time for doctors and patients, diminished quality of care, needless expense, unnecessary worry, and even the loss of lives.

Problems that arise from a lack of information do not have to happen.

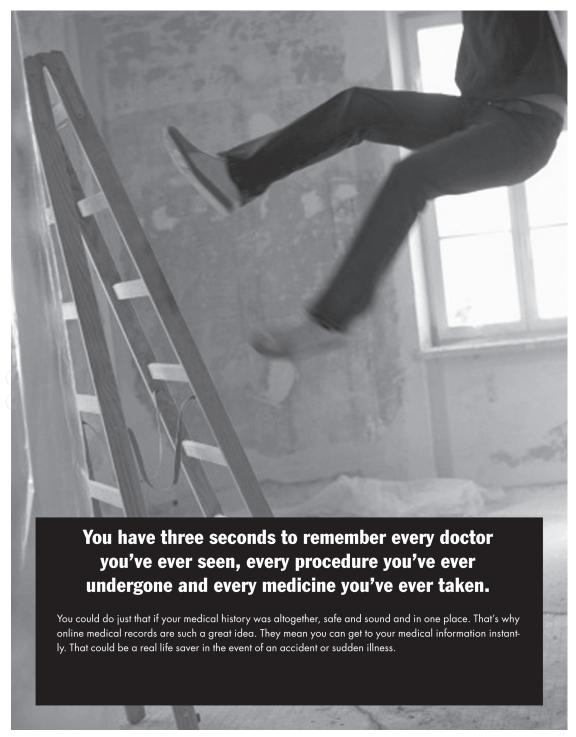
The most basic information about your health—medicines you take, tests you've had, doctors you've seen, conditions you've had—ought to be available to any doctor you choose at any time.

Once a patient has granted permission, healthcare providers should be able to access personal healthcare information when and where they need it, so they can provide the best care possible, whether the patient has a scheduled visit ... or has just fallen off a ladder.

# The Parallel to Cell Phone Technology

No one knew the extent of what could be done with cell phone technology until the market got hold of it, and gave us the cell phone-address book combination, the camera phone, the Internet-ready phone, and more. We still do not know what new uses will be developed for cell phone technology. The same holds true for a connected system of medical information.

<sup>&</sup>lt;sup>1</sup> Peggy Frank. Testimony before the Commission on Systemic Interoperability. March 15, 2005.



This document was provided by the Markle Foundation.

The U.S. healthcare system needs a connected electronic system of personal health information that allows doctors to share information and find critical data instantly. Systems that make the most of shared data and interaction are all around us: in banks, over the Internet, in libraries. Such a system for healthcare is possible. The technology exists and can be implemented—and no one can predict all the possible benefits that will arise from making it part of our lives.

### Helps healthy people stay healthy

Healthcare is episodic, but health is daily. You make decisions about your health every day, and the overall task of staying healthy is in your own hands. Healthy people stay healthy longer when they closely monitor their own health and seek out current information on how to stay well. Armed with information and knowledge, a patient not only gains new perspective on his or her choices, but also learns what the range of choices is. You choose what kinds of foods to eat, how much to eat, how much to exercise, whether or not to take vitamins, and a host of other things. Those living with chronic conditions usually monitor and maintain their health on a daily basis by, for instance, measuring blood sugar and blood pressure, or receiving outpatient therapy.

A system of electronically connected medical information will help create a more active partnership between patients and healthcare providers and promote healthier lifestyles. Doctors will be able to more easily and frequently monitor the progress of their patients, and patients will be able to more easily contact their doctors—or access a doctor's expertise through recommended articles and other material—to better follow a course of treatment.

# Problems with the paper-based system

The paper-based system of maintaining health information has critical shortcomings. There is no consistent and complete access, only limited control over access, no record of who has accessed the healthcare information, a risk of mistakes in care resulting from illegible handwriting and missing information, wasted time on tasks that could be streamlined, and no agreed-upon "language" for recording medical data.

**66** In health there is freedom. Health is the first of all liberties. >>

Henri-Frederic Amiel, Poet and Philosopher (1828 - 1881)

#### Seven "Rights"

According to Andy von Eschenbach, Director of the National Cancer Institute, there are seven "rights" to a high-quality system of healthcare:

- The **right** patient
- Receives the right treatment
- At the right time
- For the right reason
- In the right location
- With the right outcome in real time
- 7. At th

right	t pr	ice	2.2				
		(	_	(	 _	_	
					Cor	sum	ers

<sup>&</sup>lt;sup>2</sup> Andrew C. von Eschenbach. "Director's Update: Clinical Trial System of Future." NCI Cancer Bulletin (October 26, 2004): 2.

### Seven Ways to Know If Your Healthcare Provider Uses an Interoperable System of Healthcare Information

- The patient and the healthcare provider can always see the information in the record of the patient's healthcare.
- Neither the patient nor the healthcare provider ever has to reenter information that has not changed.
- The patient and the doctor can always obtain access through the system to all health studies, whether they were done in hospitals, clinics, laboratories, radiology facilities, rehabilitation centers, or nursing homes.
- 4. The patient can grant access to his or her entire health record to a healthcare provider in any part of the United States. This is especially important in the case of emergencies during travel.
- The portions of the computerbased health record necessary for business processes (e.g., payments, insurance reimbursements) can be automatically and simply provided to appropriate parties.
- The portions of the record that are relevant to quality of care studies can be readily provided.
- The patient, doctor, and participating healthcare entities are protected from improper access to private medical records by any third party under severe penalty of Federal law.

# Electronic medical records, interoperability, and the difference between the two

An electronic medical record is your current medical information and your patient history. It may include anything found in a typical paper-based file, including electronic imaging reports.

While electronic medical records have the capacity to be interoperable, they are not naturally so. That is why most existing electronic medical records cannot be used in multiple clinical care environments.

When interoperability exists, distant systems can exchange information. For instance, if you were on a trip to Los Angeles and ended up in the hospital, an interoperable system would allow your doctor there to view your entire medical history as recorded by your doctor back home, as well as any other information from any other time you had an encounter with the U.S. healthcare system.

# If paper has so many drawbacks, what is the alternative?

The better answer is connected health information—interoperability. Part of this connected information for each patient is a personal medical history, maintained on a computer: an electronic "safe" where medical history is stored. Instead of having information written on sheets of paper in filing cabinets, medical records are accessible instantly by any healthcare provider who has received permission from the patient.

What is in the interoperable electronic health record? The same things that are in a paper record: your x-rays, MRIs, prescriptions, treatment history, lab and other test results, physician's notes, and anything else you or your doctors deem important to your health.

Electronic medical information that is accessible by computer is easy for doctors to find in an emergency, because they can pull it up from wherever they are—there is no waiting for someone to rifle through a filing cabinet to find the needed information.

Consumers

### Benefits: Moral, intellectual, and practical

The possible benefits of interoperability in healthcare fall into three categories:

- The moral benefit. In 2000, the Institute of Medicine estimated that 44,000 to 98,000 Americans are killed by preventable medical errors each year.<sup>3</sup> Since that time, follow-up studies have indicated that the number of preventable deaths is even higher. For example, Health Grades, Inc. reported in 2004 that as many as 195,000 Americans were killed in 2000, 2001, and 2002 by medical mistakes in hospitals nationwide.<sup>4</sup>
- The intellectual benefit. In the 21st century, Americans should expect more from the healthcare system, a critical field that has less connectivity than many other parts of life: Kids are on-line in school, families care for grandparents through on-line services, and on-line shopping includes everything from shoes to stocks and bonds. The technology and skill exist but have yet to be purposefully applied.
- The practical benefit. An end to the document game—the problems that result from delays and inefficiencies inherent in a paper-based system of records. It is time to eliminate the shuffling of papers and the wait for critical medical information to be sent to the right person or place via phone calls, faxes, or "snail mail." An electronic system that connects caregivers and patients with information anytime and anywhere will:
  - Eliminate the need for repetitive, difficult, and often inaccurate retelling of medical history each time a patient sees a new caregiver;
  - Eliminate the one-size-fits-all approach that the lack of personal information forces on doctors and nurses as they diagnose and treat patients; and
  - Eliminate the problem of personal health information being scattered far and wide with no way to bring it together for basic healthcare, let alone emergency treatment.

<sup>&</sup>lt;sup>3</sup> L. Kohn, J. Corrigan, and M. Donaldson. *To Err Is Human: Building a Safer Health System*. Committee of Health Care in America, Institute of Medicine. 2000.

<sup>&</sup>lt;sup>4</sup> HealthGrades. *In-Hospital Deaths from Medical Errors at 195,000 per Year, HealthGrades' Study Finds.*July 27, 2004. <a href="http://www.healthgrades.com/aboutus/index.cfm?fuseaction=mod&modtype=content&modact=Media\_PressRelease\_Detail&&press\_id=135>">http://www.healthgrades.com/aboutus/index.cfm?fuseaction=mod&modtype=content&modact=Media\_PressRelease\_Detail&&press\_id=135>">http://www.healthgrades.com/aboutus/index.cfm?fuseaction=mod&modtype=content&modact=Media\_PressRelease\_Detail&&press\_id=135>">http://www.healthgrades.com/aboutus/index.cfm?fuseaction=mod&modtype=content&modact=Media\_PressRelease\_Detail&&press\_id=135>">http://www.healthgrades.com/aboutus/index.cfm?fuseaction=mod&modtype=content&modact=Media\_PressRelease\_Detail&&press\_id=135>">http://www.healthgrades.com/aboutus/index.cfm?fuseaction=mod&modtype=content&modact=Media\_PressRelease\_Detail&&press\_id=135>">http://www.healthgrades.com/aboutus/index.cfm?fuseaction=mod&modtype=content&modact=Media\_PressRelease\_Detail&&press\_id=135>">http://www.healthgrades.com/aboutus/index.cfm?fuseaction=mod&modtype=content&modact=Media\_PressRelease\_Detail&&press\_id=135>">http://www.healthgrades.com/aboutus/index.cfm?fuseaction=modact=Media\_PressRelease\_Detail&&press\_id=135>">http://www.healthgrades.com/aboutus/index.cfm?fuseaction=modact=Media\_PressRelease\_Detail&&press\_id=135>">http://www.healthgrades.com/aboutus/index.cfm?fuseaction=modact=Media\_PressRelease\_Detail&&press\_id=135>">http://www.healthgrades.com/aboutus/index.cfm?fuseaction=modact=Media\_PressRelease\_Detail&&press\_id=135>">http://www.healthgrades.com/aboutus/index.cfm?fuseaction=modact=Media\_Press\_id=135>">http://www.healthgrades.com/aboutus/index.cfm?fuseaction=modact=Media\_Press\_id=135>">http://www.healthgrades.cfm.gom/aboutus/index.cfm.gom/aboutus/index.cfm.gom/aboutus/index.cfm.gom/aboutus/index.cfm.gom/aboutus/index.cfm.gom/aboutus/index.cfm.gom/aboutus/index.cfm.gom/aboutus/index.cfm.gom/aboutus/index.cfm.gom/aboutus/index.cfm.gom/aboutus/index.cfm.gom/aboutus/index.cfm.gom/aboutus/index.cfm

### Convenience

"Never before in history has innovation offered promise of so much to so many in so short a time."

**Bill Gates** 

### You can have constant access to your own information

With an interoperable healthcare system, you will be able to review your personal medical information in private, at your leisure. You will also be able to add information as you see fit, such as family history, over-the-counter medicines you take, self-monitored data for blood sugar or blood pressure, and exercise history.

### High-touch and low-touch

With some services, you want human interaction. Other times, you just want to get what you came for and go.

At the gas station, you want to get in and out. The trend toward self-service began when the price of gas got so high that few stations could afford to pay someone to pump the gas and still maintain a competitive price. Once people began pumping their own gas, they did not want to be bothered with having to go inside to pay, and "pay at the pump" systems emerged. In 2004, more than half the transactions at gas stations happened at the pump.<sup>5</sup> It has become a "low-touch" industry.

But when you go to a nice restaurant on a special occasion, you expect personal service—"high-touch" attention. It is the same with any place where people want service tailored to their own needs. Hair salons, high-end clothing stores, auto repair shops—when people walk in, they want reassurance, handholding, and attention

In the healthcare world, high-touch attention is more than something nice to have. It is what most patients truly want, need, and expect.

<sup>&</sup>lt;sup>5</sup> Jeff Lenard. Commission on Systemic Interoperability staff interview. May 2005.

Healthcare is a hybrid—a high-touch activity that can benefit from low-touch support. It is easier to order prescriptions, make appointments, and keep up with medical records using an automated system—a low-touch approach. But when a person goes the doctor, it should be a high-attention, detail-oriented experience—a high-touch experience. However, according to the Health Resources and Services Administration, under the current system, physicians spend 38 percent of their time writing up charts.<sup>6</sup> For nurses, that figure is 50 percent.<sup>7</sup>

# Less time filling out forms

With connectivity, the first round of filling out forms can be the last round. Since all healthcare providers can share data, patients do not have to fill out a medical history or insurance form more than once. Wherever authorized providers are located (whether the patient has visited that provider before or not) the information will be readily available.

# Easier contact with your doctor means improved personal and family care

Interaction with the healthcare system is most often episodic. With an interoperable system in place, you can refer to your physician's information network and find information you need to make a doctor's appointment go more efficiently or reduce the number of follow-up visits you might have to make.

Sometimes you need to ask your doctors detailed questions in person. At other times, e-mail would be a better medium. For many questions, doctors will be able to direct you to on-line resources such as MedlinePlus.<sup>8</sup> Such a system could take into account the details of your medical condition and guide you to informative articles.

### Avoid the Redundancy and Possible Error of Retelling Medical History

Nearly everyone has had the experience of going to a new doctor or hospital and having to fill out a huge pile of forms. Those forms usually include a request for medical history, something most people will have given to other healthcare providers several times before. When recounting that history, there is always the risk of forgetting something. People with many health problems cannot be expected to remember all the details of their treatment.

Even the healthiest person can have a lengthy record, and the dates and details can be impossible to remember. In an emergency, a reliable recounting is even less likely and even more critical. For patients with chronic conditions, retelling a medical history is often quite emotional and painful and omissions can be deadly.

An interoperable healthcare system will eliminate the need for retelling medical history by making that history available to every provider authorized by the patient and by allowing doctors and others to add to the history as treatment progresses. The system will minimize and ultimately eliminate the need to transmit medical records by phone, fax, courier, or mail.

<sup>&</sup>lt;sup>6</sup> Bill Finerfrock. "Presentation on Electronic Medical Records in Rural Health Clinics" (teleconference transcript). Health Resources and Services Administration. 2005.

<sup>&</sup>lt;a href="http://ruralhealth.hrsa.gov/RHC/March16Transcript.htm">http://ruralhealth.hrsa.gov/RHC/March16Transcript.htm</a>

<sup>7</sup> Ibid.

<sup>8</sup> URL: www.medlineplus.gov. MedlinePlus allows consumers to conduct free searches for up-to-date medical information, including extensive information about drugs, an illustrated medical encyclopedia, interactive patient tutorials, and the latest health news. MedlinePlus also provides access to medical journal articles.

A connected system makes it easier for parents to obtain copies of vaccination and other medical records for camp and school. It eases the task of caring for aging parents. It also provides a way for patients to get the information they need to ease their own health concerns.

#### Millions of Adults Monitor Healthcare of a Loved One from a Distance

According to a survey conducted by the Family Caregiver Alliance,<sup>9</sup> over seven million Americans are managing care for a loved one over age 55 who lives at least an hour away. Caring for an aging parent is hard enough, and distance only increases the difficulty.

According to the same survey, the average long-distance caregiver lives 450 miles away from the loved one he or she is caring for. Those polled reported spending an average of \$392 a month for out-of-pocket expenses and travel, not counting missed job time and income.

### On-line Support: One Patient's Experience

In 2003, Pat McGinley of Cleveland, Ohio, registered for an on-line program created to help patients monitor their health. She signed up at the request of her physician, but it never crossed her mind that she would actually use it. "I am not a real techie person," she said. "I did it to appease my doctor." A few weeks later, following routine blood work, the doctor's nurse called to inform her that she had both high cholesterol and high triglyceride levels. Pat was upset at the news and resigned herself to living with her worries and unanswered questions until the follow-up visit in two weeks.

Then something happened that Pat did not expect: She received an e-mail telling her that she should log on to her on-line healthcare program to review new information. She went from being worried to being relieved when the program directed her to comprehensive, easy-to-understand information about her test results and likely condition. She could compare her results with normal levels and click on embedded links for additional material. Pat began to feel more at ease, and at her next appointment she was prepared with important, informed questions for her doctor about her health and what she needed to change.

The system "really empowered me to think about what was going on. It made me feel like I was part of the decision-making process," she told President Bush at a public event at the Cleveland Clinic in January 2005.

With the help of an interoperable healthcare system, Pat and her doctor were able to work together to make critical lifestyle changes. As a patient, Pat understood her medical situation better than she ever had before, and she credits that to her access to private, personalized information delivered electronically. "I went from feeling helpless to feeling completely in control of the situation," she said.<sup>10</sup>

<sup>&</sup>lt;sup>9</sup> Michael Hill. "Moving Creates Boom in Long Distance Care," Washington Post. March 17, 2005.

White House Office of the Press Secretary. President Discusses Health Care Information Technology Benefits. Press release. January 27, 2005.

<sup>&</sup>lt;a href="http://www.whitehouse.gov/news/releases/2005/01/20050127-7.html">http://www.whitehouse.gov/news/releases/2005/01/20050127-7.html</a>

# **Empowering Patients and Improving Care**

"Health IT can enable transformation of healthcare by allowing a better way to care—consumer by consumer, physician by physician, disease by disease, and region by region."

David Brailer, M.D., Ph.D., National Coordinator for Health Information Technology

### **Continuity of care**

With accessible personal health information, each new caregiver a patient sees can have access to that patient's history as the patient sees fit. Doctors no longer have to worry that the medications and the course of treatment they prescribe may be in conflict with those prescribed by other providers. In short, an interoperable system of electronic health information allows not only doctors but also hospitals, pharmacies, insurance providers, labs, diagnostic centers, nursing facilities, assisted living centers, and hospices to see the big picture—to know and understand the courses of treatment in progress, the intentions and goals of other healthcare providers, and the details and general trends of a patient's health and courses of treatment.

In addition to helping patients who see multiple doctors, the system will help ensure continuity of care for people who have moved from one place to another, an important benefit in a mobile society. How frequently does this issue come up for people? A study by the Commonwealth Fund, a private foundation supporting research on medically underserved communities, shows that nearly two-thirds of adults change doctors at least once every five years.<sup>11</sup>

### Fewer errors and less wasted time

Since patients can give any provider access to their medical records any time, anywhere, they will no longer have to recount their medical histories every time they see a new doctor. That means that everyone saves time and there is no risk of forgetting a critical detail of treatment or condition.

#### An Increasingly Mobile Society

Americans are refusing to stay put and today's technology reflects that more and more. People travel greater distances frequently, whether for business or pleasure.

Visiting family, moving around the country to find work, traveling on business... all of these realities create huge demand for new technologies and devices to accommodate busy lives and constant motion. Personal digital assistants, cell phones, laptop computers, wireless Internet access, portable DVD and MP3 players, and Global Positioning Systems are just some of the gadgets that are available to the average consumer.

Amazingly, though, our cars benefit from more connectivity than our bodies do. If your car breaks down, you can take it to almost any dealership service department where the mechanic can access a history of the work that has been performed on that car and make an appropriate decision on what to do next.

Healthcare should be no different. In today's economy and travel culture, even healthcare professionals are more mobile than they were just a few decades ago. Healthcare information should be mobile and available wherever patients and professionals happen to be. Your health information should be designed to travel with you, not limit your travel.

Harris Interactive. 2004 Commonwealth Fund International Health Policy Survey of Adults' Experiences with Primary Care, Commonwealth Fund. 2004 <a href="http://www.cmwf.org/surveys/surveys\_show.htm?doc\_id=245240">http://www.cmwf.org/surveys/surveys\_show.htm?doc\_id=245240</a>

educated you become, the more educated you become, the more comfortable you become, not only about figuring out what's wrong, but, more importantly, figuring out how to cure the problem.

President George W. Bush (on patient-accessible electronic medical records)

### Both doctors and patients are better informed

Healthcare providers will also be able to monitor compliance to find out if patients are getting their prescriptions filled, following up with referred physicians, and getting tests as ordered. Patients will be able to access the details of their treatment on the network and read as much or as little about their condition as they like. When health information is made available by doctors for patient review, the patients will be more informed, better prepared to ask questions, and better able to find peace of mind.

### Better management of chronic conditions

Diabetes and other chronic conditions require frequent monitoring. Seven out of every 10 deaths in the United States each year are attributed to chronic diseases such as cancer, arthritis, muscular dystrophy, diabetes, and cardiovascular disease. <sup>12</sup> These often are prolonged illnesses that decrease quality of life and cause critical physical limitations, and they affect 90 million Americans. <sup>13</sup> When patients follow the treatments doctors prescribe and make lifestyle changes, such as getting more exercise, they can better manage chronic diseases.

Communication between doctors and patients can improve the management of chronic diseases, because patients will have a better understanding of their condition, how to manage pain, and how to deal with personal limitations. Chronic diseases often manifest themselves in ways that appear minor but are in fact significant indicators of serious problems. With better communication, patients can learn to recognize these symptoms so they can properly manage their healthcare.

# **Electronic prescribing (e-prescribing)**

With an electronic healthcare system in place, doctors' prescriptions will instantly be sent to a pharmacy for patients to pick up. The prescription will be signed with an electronic signature that is readable at the pharmacy, so the notoriously illegible handwriting of doctors will no longer be an issue. There will be no paper

<sup>12</sup> National Center for Chronic Disease Prevention and Health Promotion. <a href="http://www.cdc.gov/nccdphp/">http://www.cdc.gov/nccdphp/</a>

<sup>13</sup> Ibid.

prescriptions to lose or to drop off at the pharmacy, so patients will save time, trips to the doctor, and phone calls. E-prescribing systems will be able to check for harmful drug interactions as the doctor writes the prescription, long before the patient picks it up at the pharmacy.

### Improved care for expectant mothers and their unborn babies

Obstetrics is an ideal place to introduce patients to connected healthcare information. On average, a pregnant patient will visit her provider's office 14 times during the pregnancy, 14 more than any other time in her life. Since prenatal exams may occur at many different locations, and different practitioners in a group may examine the same patient, interoperable records promote continuity of prenatal care. Expectant mothers may go into labor at unexpected times or places; accessible health information ensures that the mother's history is always available, wherever and whenever the delivery takes place.

# Makes personalized care possible as future medical advances warrant

Medical advances such as DNA research might reveal that medicines will have different effects on people depending on their genetic makeup. Today a doctor may adjust a dosage on the basis of a patient's weight. In the future, a doctor will be able to order medications with specific characteristics, probably down to the molecular level, depending on the genetic makeup of a patient.

To take full advantage of these precise, customized medications, physicians will need access to voluminous and complex genetic information about a patient. These details will not be as simple as dates of treatment and names of conditions; that is, they cannot be memorized or easily carried around. These details will be stored in secure computer data files. For patients to benefit from new medicines, authorized healthcare providers will need to be able to review personal health information through an interoperable healthcare system.

Consumers

<sup>&</sup>lt;sup>14</sup> Donald Miller. "Prenatal Care: A Strategic First Step Toward EMR Acceptance." Journal of Healthcare Information Management 17, no. 2 (2003): 47–50.

# **Confidentiality, Privacy, and Security**

"We want to know that the record is secure and that it remains confidential. But information technology actually works perfectly to document that. If you left a medical record on paper in a room, how will you know who saw it? You can't know. When it's in electronic form, when anyone logs on to the system, we know. We know who they are, we know where they are, we know what they were looking at, and we can keep logs of all that information so that we can confirm for our patients that their information is secure."

#### Dr. C. Martin Harris, Cleveland Clinic

#### Common Electronic Transactions

ATMs. 371,000 ATMs processed 10.8 billion transactions in 2003 in the United States. That is about 80 transactions a day or about 29,000 each year per ATM.<sup>15</sup>

**Buying movie tickets on-line.**Nearly one in four moviegoers has purchased tickets on-line.<sup>16</sup>

**Travel.** 39 million people booked travel on-line in 2002, an increase of 25 percent over 2001.<sup>17</sup>

Banking. The 29.6 million U.S. households banking on-line in 2003 is forecast to increase to 56 million by 2008.<sup>18</sup>

**Income taxes.** Over half of all income tax forms in the 2005 tax season were filed on-line.<sup>19</sup>

### The power of technology to create trust

When it comes to using technology—actually making it a part of day-to-day life—attitudes have changed dramatically in a short period of time. Not so long ago, many people were intimidated by and distrustful of computers, but now most people welcome them and wonder how life went on without them:

- Most people enjoy 24/7 access to cash through ATMs;
- Fewer checks are used because of debit and credit card readers in stores;
- Computers in your car tell you when you are due for maintenance, how much gas is left in the tank, how many miles you have traveled and how many you have to go, and even the temperature outside. Global Positioning Systems tell you exactly where you are, and how to get where you are going;

<sup>&</sup>lt;sup>15</sup> Miller, Donald. "Prenatal Care: A Strategic First StepToward EMR Acceptance." Journal of Healthcare Information Management 17.2 (2003): 47-50.

<sup>16 &</sup>quot;This Summer's Blockbuster Hit: The Internet." Freelance Writing. July 2004. <a href="http://www.freelancewriting.com/survey-072004-01.html">http://www.freelancewriting.com/survey-072004-01.html</a>

Mintel International Group Ltd. "InternetTravel: Abstract." September 1, 2003.
<a href="http://www.marketresearch.com/product/print/default.asp?g=1&productid=931785">http://www.marketresearch.com/product/print/default.asp?g=1&productid=931785</a>

<sup>&</sup>lt;sup>18</sup> Kim Komando. Online Banking's Best Lure: Online Bill Paying. Microsoft: Small Business Center. 2005. <a href="http://www.microsoft.com/smallbusiness/resources/technology/business\_software/online\_bankings\_best\_lure\_online\_bill\_paying.mspx">http://www.microsoft.com/smallbusiness/resources/technology/business\_software/online\_bankings\_best\_lure\_online\_bill\_paying.mspx</a>

<sup>&</sup>lt;sup>19</sup> Internal Revenue Service. 2005 Tax Filing Season Sets Records. July 2005. <a href="http://www.irs.gov/newsroom/article/0,,id=138112,00.html">http://www.irs.gov/newsroom/article/0,,id=138112,00.html</a>

Cell phones are small, specialized computers. You can make calls wherever
you are, and you are not limited by wires and cords. Some cell phones
compete with desktop computers in their ability to accommodate e-mail,
Internet access, word processing, and even photographs and video.

# Why Americans (and the world) have so readily adopted technology

Your most personal and important information is entrusted to secure electronic systems. That security is one key to quick and widespread acceptance of connected healthcare systems.

It was not just convenience and fun that earned technology mainstream acceptance. A critical concern was first addressed: Would personal information such as tax returns and bank accounts be kept private? Had technology been introduced to the U.S. culture through government efforts, legislators could have simply mandated the use of interoperable systems, then improved the system after they were in place.

But private investors in technology could take no such risks. Privacy and security issues had to be anticipated and resolved by the businesses creating the systems. The public had to accept a system's security, then make their opinion known by using the system—or by turning it into a very expensive white elephant.

For the ATM network, on-line banking, bill paying, and e-commerce to succeed, the system had to thoroughly protect privacy. And the public had to believe—correctly—that the system was reliable as advertised. This confidence in technology was acquired incrementally. The benefits were great enough for Americans to assume a relatively minor risk.

has radically changed business and so many other aspects of American life. It is time we use the power of the information age to improve health care. If we do, we can dramatically improve the quality of care, safety, efficiency and patient control over their health care decisions.

Statement by Senate Majority Leader Bill Frist and Senator Hillary Rodham Clinton



# Trusting Technology at the Gas Pump

How often do you take a receipt after filling up your gas tank and paying with a card? When you do take the receipt, do you usually throw it away after looking at it? When the bill comes at the end of the month, do you just assume it is correct, or do you go through a stack of paper receipts to reconcile it?

Most people discard the receipt if they take a look at it at all, and when the bill comes in they glance at the total to make sure the bill is in the normal price range.

This example of trusting technology to consistently get important details right is a good indicator that people will eventually trust technology with other critical information—such as personal healthcare records.

# People are growing more comfortable with using technology for healthcare

Trust in technology's ability to protect privacy is beginning to spread to its use for medical information:

- Eight in 10 Internet users—about 95 million Americans over the age of 18—have looked on-line for health information.<sup>20</sup> They are especially interested in diet, fitness, drugs, health insurance, experimental treatments, and particular information about doctors and hospitals.<sup>21</sup>
- Fifty-nine percent of women who go on-line have read up on nutrition.<sup>22</sup>
- Thirty-eight percent of parents on-line have checked for health insurance information.<sup>23</sup>
- Forty-one percent of Internet users with broadband connection at home have looked up a doctor or hospital.<sup>24</sup>

This is an encouraging start, but the level of American confidence needs to be much higher for an interoperable healthcare system to be accepted. Over 70 percent of people want to see technology used to improve the quality of healthcare, but nearly as many (67 percent) are concerned about privacy.<sup>25</sup>

<sup>&</sup>lt;sup>20</sup> Susannah Fox. "Eight in Ten Internet Users Have Looked for Health Information Online, with Increased Interest in Diet, Fitness, Drugs, Health Insurance, Experimental Treatments, and Particular Doctors and Hospitals." Health Information Online. May 17, 2005.
<a href="https://www.pewinternet.org/PPF/r/95/report\_display.asp">www.pewinternet.org/PPF/r/95/report\_display.asp</a>

<sup>21</sup> Ibid.

<sup>&</sup>lt;sup>22</sup> Pew Internet. More Internet Users Do 'Health Homework' Online. Press release. May 17, 2005. <a href="http://www.pewinternet.org/press\_release.asp?r=106">http://www.pewinternet.org/press\_release.asp?r=106</a>>

<sup>&</sup>lt;sup>23</sup> Susannah Fox. "Eight in Ten Internet Users Have Looked for Health Information Online, with Increased Interest in Diet, Fitness, Drugs, Health Insurance, Experimental Treatments, and Particular Doctors and Hospitals." Health Information Online. May 17, 2005.
<a href="http://www.pewinternet.org/PPF/r/95/report\_display.asp">http://www.pewinternet.org/PPF/r/95/report\_display.asp</a>

<sup>24</sup> Ibid.

<sup>&</sup>lt;sup>25</sup> Harris Interactive. "Many Nationwide Believe in the Potential Benefits of Electronic Medical Records and Are Interested in Online Communications with Physicians." August 2005. <a href="http://www.harrisinteractive.com/news/allnewsbydate.asp?NewsID=895">http://www.harrisinteractive.com/news/allnewsbydate.asp?NewsID=895</a>

# The good news: Prevention and confidentiality are attainable goals

No system can be perfect, but you can expect much higher quality outcomes from an electronic healthcare system than you receive from the current paper-based system. After all, most electronic information systems perform flawlessly every day. If they didn't, bank accounts would be wrecked and bills would be inaccurate every month.

That is not to pretend there are no problems in the world of electronic data exchange. But those problems are the exception, not the rule. For every incident of lost data, billions of transactions occur without incident every day. Still, recent events involving data loss deserve consideration. The following information was published by the *Wall Street Journal* in May 2005:<sup>27</sup>

In February 2005, consumer-data compiler ChoicePoint announced the theft of data on about 145,000 consumers. Within two weeks of that incident, Bank of America announced the loss of up to 1.2 million credit card numbers belonging to the Federal government. In March, retailer DSW Shoe Warehouse announced the discovery of theft of data potentially affecting over a million people. In June, CardSystems Solutions Inc., a payment processing company, was infiltrated by hackers, exposing more than 40 million credit card and debit card accounts to potential fraud. Similar events followed at Lexis-Nexis, Boston College, Polo Ralph Lauren, Ameritrade, and Time-Warner.

In some cases, fraud against consumers was discovered quickly. In other cases, customers were advised to closely check their credit card statements for several months to make certain fraudulent charges did not appear. In a few cases, the problem was not data theft but the loss of backup data media, such as reels of computer tape during shipping; this would have led to fraud only if the tapes had been found, identified, and translated.

### The Living Will Registry: An Application of Electronic Connections in Healthcare

More and more Americans are writing "living wills"—instructions for medical care in the event that they become too incapacitated to communicate with their doctors. It's a good idea, but the problem with a living will is that healthcare providers do not always know that their patient has one.

That is why, in 1996, Joseph Barmakian, MD, created the U.S. Living Will Registry.26 The registry is a way to provide instant access to physicians nationwide for patients who maintain a living will. In fact, healthcare providers are required by Federal law to check for a patient's advance directive and place a copy of the will in the patient's medical record. Access to the registry is password-protected, and a patient's information is shared with no one other than his or her healthcare provider. This service is provided free to the public.

<sup>&</sup>lt;sup>26</sup> United States Living Will Registry. "Living Will—Health Care Proxy." July 2005. <a href="http://www.uslivingwillregistry.com/info-english.shtm">http://www.uslivingwillregistry.com/info-english.shtm</a>

E. Perez and R. Brooks. "File Sharing: For Big Vendor of Personal Data, ATheft Lays Bare the Downside." Wall Street Journal. May 3, 2005.

Consumar

### The Limits of Security: An Important Note

While a system of interoperable health information can be designed to carefully monitor the access and use of information, it's not possible to ensure that there are absolutely no "prying eyes." The limits of safeguards will be determined primarily by the state of technology. Today, unauthorized use is minimized by log-ins and passwords for authentication that limit access to medical information. In time, the system will be strengthened with biometrics. Improvements will also be made in encrypting data during storage and transfer. But even the most basic system of connected health information will provide more consistent security and improved tracking of access than any paper system can.

While all data loss is potentially serious, these events are notable for their real-life impact relative to the number of records lost or stolen:

- At ChoicePoint, only 750 cases of fraud appeared out of the records of 145,000 consumers—about one-half of one percent.
- At Lexis-Nexis, only 59 incidents have been reported out of stolen information on 310,000 consumers—0.019 percent, or less than two-hundredths of one percent.

The organizational responses to these incidents are promising. In each case, the organization modified the way it handled consumer information to improve the systems of protection:

- Bank of America is moving away from backup tapes to computer-tocomputer data transfers. In instances where backup tapes cannot be eliminated, encryption is being considered.
- Since the thieves posed as legitimate customers, ChoicePoint no longer sells sensitive personal data to clients outside government and accredited corporate entities.
- Lexis-Nexis reduced access to personal data.<sup>28</sup>

All the companies worked with Federal authorities to find the culprits and to improve procedures for security.

Public confidence in these companies has remained strong, as measured by the value of the companies' stock and their sales. While stock prices for some of the companies took an immediate dip when the breaches were publicized, almost every firm has rebounded. Polo Ralph Lauren's stock price dropped 55 cents (1.4 percent) the day it confirmed data theft;<sup>29</sup> however, quotes bounced back to near 52-week highs in late June. DSW Shoe Warehouse's sales actually saw a considerable increase; revenues grew more than 60 million dollars (not adjusted for inflation) for the first five months of 2005 compared with 2004.<sup>30</sup> Other

<sup>&</sup>lt;sup>28</sup> Lucas Mearian. "Data Snafus Spur IT Action: Bank Mishap Prompts Call for Network Backup." COMPUTERWORLD. March 7, 2005. <a href="http://www.computerworld.com/?source=nav\_tab">http://www.computerworld.com/?source=nav\_tab</a>

<sup>&</sup>lt;sup>29</sup> Associated Press. "Update 5: Polo Ralph Lauren Customers' Data Stolen." Forbes. June 2005. <a href="http://www.forbes.com/business/feeds/ap/2005/04/14/ap1947570.html">http://www.forbes.com/business/feeds/ap/2005/04/14/ap1947570.html</a>

<sup>30</sup> J. McGrady. "May Sales Report." Retail Ventures (June 2005). <a href="http://www.retailventuresinc.com/index.isp">http://www.retailventuresinc.com/index.isp</a>

companies, such as Time-Warner and Bank of America, showed no significant fluctuation in stock prices.

If consumer confidence was shaken, that confidence seemed to return quickly.

### Individuals want access to and control of their own records

Dr. Alan Westin is a retired professor at Columbia University and a widely recognized advocate for privacy rights. He has examined the task of winning public support for a system of electronic health records.

Dr. Westin conducted a survey to see if people believe that the expected benefits of a system—whatever they think those benefits might be—outweigh the potential risks to privacy.<sup>31</sup> In his survey, Dr. Westin asked whether consumers think it is important to be able to track their own information and "exercise privacy rights." The result was no surprise: More than 80 percent of the respondents rated availability of their medical records as important.<sup>32</sup>

As a connected electronic healthcare system is integrated into the practice of healthcare, the system must be transparent—each element of an interoperable system must be fully known to the public, its function clearly understood, and its mechanisms available for inspection. Explanations to the public must use straightforward language to create confidence and must acknowledge—not dismiss—doubt. In particular, the system should allow individuals:

- To access personal clinical data;
- To make additions to the record; and
- To review the audit trail of who accessed the records, what was viewed, when, and for how long.

32 Ibid.

Consumers

<sup>&</sup>lt;sup>31</sup> Alan Westin. How the Public Views Health Privacy: Survey Findings from 1978 to 2005. PrivacyExchange. February 23,2005. <a href="https://privacyexchange.org/">https://privacyexchange.org/</a>

There is no more direct way for people to check the accuracy of their records than to simply review the information themselves.

At the launch of the interoperable healthcare system, any particular piece of information will almost certainly be maintained at its source (e.g., lab reports at the lab or at the office of the requesting physician, treatment records at the doctor's office, hospital records at the hospital). This may change as new technologies emerge and are implemented, but security, confidentiality, and transparency to patients must remain top priorities in deciding how and where data are stored.

### Confidentiality: The core of the doctor-patient relationship

The core of healthcare is the relationship between the patient and the provider. That relationship is built on trust—not an abstract notion of confidentiality or security, but a personal belief that what a patient tells a doctor or nurse remains confidential.

In a healthcare relationship, individuals disclose highly confidential—sometimes embarrassing and definitely private—information about themselves, information they may not tell anyone else.

Doctors need to know this information to better understand a patient's problem and to better prescribe treatment. There is no other way to deliver the right care.

Technology cannot be allowed to disrupt this relationship. Rather, technology must fit seamlessly into the existing "psychology of trust" found in the healthcare world. The trust a patient holds in a healthcare provider helps build trust in new elements added to the healthcare system, leading to an attitude of, "If my doctor trusts this new system, then I do, too." Doctors will need concrete facts to tell their patients about the security and privacy of the system. Companies that provide systems will need to support physicians and hospitals in efforts to educate patients.

### **Health Issues for Individual Communities**

"Information technology holds the promise of reducing healthcare disparities for those living in rural communities. We can measure our success in building an IT infrastructure by the provision of quality of care in these communities challenged by long distances and scarce medical resources."

**Senator Chuck Grassley** 

# Access for everyone, including the poor and indigent

The need for healthcare is universal and critical, and a system of accessible and accurate interoperable records can extend benefits to everyone. It would not merely equalize healthcare opportunities; it could raise the quality of healthcare for everyone. This is especially important for the indigent and the working poor populations, who often have the most challenging healthcare issues and the least continuity of care.

# Better care in community health centers

Thirty-six million Americans lack access to a regular source of healthcare—that is nearly one out of every eight people.<sup>34</sup> Twenty-six percent of all health center visits are for chronic diseases, including asthma, diabetes, hypertension, HIV/AIDS, mental health issues, and substance abuse.<sup>35</sup> These centers serve:

- One in eight uninsured Americans;
- One in five low-income uninsured Americans;
- One in nine Medicaid beneficiaries;
- One in seven members of minority groups;

### Connecting Migrant Workers

The health problems of migrant workers are often compounded by constant travel, along with language and cultural barriers. But a new system in Sonoma County, California, is changing that. This interoperable healthcare network allows migrant workers and their families to enroll in a program that stores their health history, conditions, and treatments as an electronic health record. The records can be accessed by healthcare providers from clinics anywhere in the United States and Mexico 33

ate	5 8	inc	IVI	ex	ico	
		)				
						Consumers

<sup>33 &</sup>quot;Internet Medical Records for Migrant Workers." Local Frontiers-Sonoma Medicine 55, no. 2 (Spring 2004). <a href="http://www.vwsvia.org/">http://www.vwsvia.org/</a>

<sup>34</sup> National Association of Community Health Centers. A Nation's Health at Risk. 2004.

<sup>35</sup> Ibid.

- · One in ten Americans living in rural areas; and
- One in five low-income children.<sup>36</sup>

The following are among the benefits of an interoperable system to individuals who rely on these centers:

- Preventing abuse by checking all medications taken and supplying only appropriate medications;
- Providing accurate records of immunizations for children; and
- Preventing chronic disease with more effective primary care for patients through monitoring of conditions and adherence to treatment.<sup>37</sup>

### Issues in rural areas

Four-fifths of the United States is rural,<sup>38</sup> and in 29 states at least one-third of the population is classified as rural. Rural residents face serious healthcare issues not only in terms of illness but also in terms of lack of easily accessible services. For instance:

- One in five Americans live in rural areas but only one in 10 physicians practice in rural areas;<sup>39</sup>
- Forty percent of the rural population lives in a medically underserved area;<sup>40</sup>
- Fire departments are the primary provider of medical services in rural areas;<sup>41</sup>

<sup>36</sup> Ibid.

<sup>37</sup> Ibid.

<sup>&</sup>lt;sup>38</sup> For practical purposes, "rural" can be considered areas of relatively low population outside cities and suburbs. "Urban" can be considered the cities and suburbs themselves. For purposes of analyzing statistics, consider the U.S. Census Bureau definitions: "urban" is "[a]II territory, population and housing units in urban areas, which include urbanized areas and urban clusters. An urban area generally consists of a large central place and adjacent densely settled census blocks that together have a total population of at least 2,500 for urban clusters, or at least 50,000 for urbanized areas. Urban classification cuts across other hierarchies and can be in metropolitan or non-metropolitan areas." "Rural" is "[t]erritory, population and housing units not classified as urban ... and can be in metropolitan or non-metropolitan areas." Source: U.S. Census Bureau. "Urban and Rural Definitions." October 1995.

<sup>&</sup>lt;sup>39</sup> Gary Erisman. "Rural Emergency Response–The Safety and Health Safety Net." National Ag Safety Database. 2001. <a href="http://www.cdc.gov/nasd/docs/d001701-d001800/d001781/d001781.pdf">http://www.cdc.gov/nasd/docs/d001701-d001800/d001781/d001781.pdf</a>

<sup>40</sup> Ibid.

<sup>&</sup>lt;sup>41</sup> Bruce Evans. "Rural Health Care's Missing Link." Fire Chief. June 2002.

- For motor vehicle accidents, the average response time of emergency medical services in rural areas is 18 minutes. 42 This is eight minutes longer than the response time in urban areas. 43 (The average response time from the point of injury to the arrival of medical assistance for transport during the Vietnam War was eight to 10 minutes); 44
- Compared with patients in urban areas, patients in rural areas tend to be older, have higher rates of chronic illness, and exhibit poorer health behaviors such as smoking and obesity;<sup>45</sup> and
- Rural residents often have to travel great distances to reach medical care. 46

With access to care an average of 30 miles away,<sup>47</sup> rural areas have much to gain from the ability to access healthcare information at a distance. In an emergency, interaction with a doctor may be limited to phone advice. For routine care, increased communication with healthcare providers will increase patients' quality of life because they can better follow treatment guidelines and more easily receive feedback from healthcare providers. This is especially valuable for the many rural areas that offer few preventive services.

The American Indian and Alaskan Native populations most often live in rural areas, and their healthcare problems mirror many of those of the rural population. Like the rural population, these individuals tend to have more serious and more frequent health problems than the general population, and they enjoy less access to the healthcare system. As a result, they tend to use health services less often than other groups.

44 Gary Erisman. "Rural Emergency Response—The Safety and Health Safety Net." National Ag Safety Database. 2001. <a href="http://www.cdc.gov/nasd/docs/d001701-d001800/d001781/d001781.pdf">http://www.cdc.gov/nasd/docs/d001701-d001800/d001781/d001781.pdf</a> >

<sup>&</sup>lt;sup>42</sup> National Rural Health Association. What's Different About Rural Health Care? July 2005. <a href="http://www.nrharural.org/about/sub/different.html">http://www.nrharural.org/about/sub/different.html</a>

<sup>43</sup> Ibid.

<sup>&</sup>lt;sup>45</sup> American Society of Health-System Pharmacists. "IOM Sets Strategy for Improving Rural Health Care Quality." December 15, 2004. <a href="http://www.ashp.org/news/showArticle.cfm?cfid=19987294&CFToken=93416380&&id=8935">http://www.ashp.org/news/showArticle.cfm?cfid=19987294&CFToken=93416380&&id=8935</a>

<sup>46</sup> National Rural Health Association. "What's Different About Rural Health Care?" July 2005. <a href="http://www.nrharural.org/about/sub/different.html">http://www.nrharural.org/about/sub/different.html</a>

<sup>&</sup>lt;sup>47</sup> Bruce Evans. "Rural Health Care's Missing Link." Fire Chief. June 2002.

An Institute of Medicine committee has recommended that the government develop a strategy for transitioning rural health clinics (along with community health centers, critical access hospitals, and other rural providers) from paper to electronic health records.<sup>48</sup>

### Tracking disease and nationwide medical concerns

A connected system of healthcare would allow the U.S. government to monitor health concerns such as vaccination rates, disease outbreaks, and disease trends nationwide. This kind of bio-surveillance would mean that West Nile virus, avian influenza, environmental health concerns, disease outbreaks from flooding due to hurricanes, such as Hurricane Katrina, and numerous other issues could be better targeted and monitored, allowing containment efforts to be established with more precision and efficiency.

**66** You won't find a solution by saying there is no problem. **99** 

William Rotsler, Author (1926 – 1997)

### **Military**

The U.S. military service branches do not have an efficient way to transmit medical information in critical, time-sensitive situations. For soldiers extracted from the battlefield, injury notes, medical history, test results, and surgical history are not always communicated from one doctor to the next. This forces servicemen to undergo duplicate tests and surgeries, and to settle for less than the most efficient treatment.

### Veterans

The U. S. Department of Veterans Affairs (VA) currently provides medical care for over five million veterans.<sup>49</sup> The VA maintains electronic copies of all patient information—including information from doctor's appointments, medications, and laboratory and imaging data—constituting a closed interoperable network of healthcare information for this specific population. Any of this information can be stored and transmitted among doctors within the VA medical system. The success of this system suggests that a nationwide system of connected health information is possible.

<sup>&</sup>lt;sup>48</sup> American Society of Health-System Pharmacists. "IOM Sets Strategy for Improving Rural Health Care Quality." December 15, 2004. <a href="http://www.ashp.org/news/showArticle.cfm?cfid=19987294&CFToken=93416380&&id=8935">http://www.ashp.org/news/showArticle.cfm?cfid=19987294&CFToken=93416380&&id=8935</a>

<sup>&</sup>lt;sup>49</sup> United States Department of Veterans Affairs. Facts About the Department of Veterans Affairs. June 2005. <a href="http://www1.va.gov/opa/fact/vafacts.html">http://www1.va.gov/opa/fact/vafacts.html</a>

# Reducing Medical Errors While Saving Patients' Time and Money

"Today in America, thousands of patients are having unnecessary tests, undergoing surgeries they do not need, and taking harmful drugs due to our paper-based health care system, and the consequences are deadly and costly. Because of this, sadly, hundreds of patients will die today and thousands more will be put at risk. And all of this can be prevented. Simply put, paper kills."

Congressman Tim Murphy

### The bottom line

Medical errors are killing more people each year than breast cancer, AIDS, or motor vehicle accidents.<sup>50</sup>

### The scope of the problem: by the numbers

- One of every seven primary care visits is affected by missing medical information, leading to duplication of, or delays in, care and testing, along with unnecessary costs to the patient.<sup>51</sup>
- According to the Center for Information Technology Leadership, approximately one-fifth of medical errors are due to inadequate availability of patient information.<sup>52</sup>
- In an article published in the July/August 2004 issue of *Annals of Family Medicine*,<sup>53</sup> medical errors were studied as a chain of events rather than isolated incidents. Two-thirds of all errors in treatment and diagnosis were found to begin with errors in communication. These included missed communication among physicians, misinformation in medical records, mishandling of patient requests and messages, inaccessible records, mislabeled specimens, misfiled or missing charts, and inadequate reminder systems.

<sup>&</sup>lt;sup>50</sup> Institute of Medicine, Centers for Disease Control and Prevention; National Center for Health Statistics: Preliminary Data for 1998 and 1999. 2000.

<sup>&</sup>lt;sup>51</sup> Peter Smith. "Missing Clinical Information During Primary Care Visits," Journal of the American Medical Association. 2005.

<sup>&</sup>lt;sup>52</sup> Global Technology Centre. Reactive to Adaptive: Transforming Hospitals with Digital Technology. 2005.

<sup>&</sup>lt;sup>53</sup> Woolf, Steven H. A String of Mistakes: The Importance of Cascade Analysis in Describing, Counting, and Preventing Medical Errors. Annals of Family Medicine 2:317-326 (2004). <a href="http://annalsfm.highwire.org/cgi/content/abstract/2/4/317">http://annalsfm.highwire.org/cgi/content/abstract/2/4/317</a>>

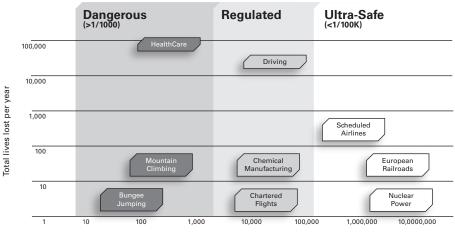
- According to a survey by Research America, 41 percent of Americans have been or know someone who has been the victim of a medical error.<sup>54</sup>
- According to the Institute of Medicine, over a half million people are injured each year because of adverse drug events, many of which could be avoided if healthcare providers had complete information about which drugs their patients were taking and why.<sup>55</sup>

### Relative risk of healthcare

Of activities seen as potentially risky, travel by rail in Europe and commercial air travel are actually among the safest activities, with fewer than one in 100,000 fatalities per personal encounter or trip. Driving is far more dangerous: about 42,000 people die each year in automobile accidents. It is no surprise that, statistically, mountain climbing and bungee jumping are among the most dangerous activities. But the biggest surprise of all is there are more deaths per encounter with the healthcare system than for any of these other activities. <sup>56</sup>

#### How Hazardous is Healthcare?

Source: Agency for Healthcare Research and Quality (AHRQ)



Number of encounters for each fatality

Wooley, Mary. Research for Health: The Power of Advocacy. January 14 2005. Research! America. PowerPoint. January 14, 2005. <a href="http://www.nlm.nih.gov/csi/research\_america\_011405.pdf">http://www.nlm.nih.gov/csi/research\_america\_011405.pdf</a>

<sup>55</sup> Agency for Healthcare Research and Quality. "Reducing and Preventing Adverse Drug Events to Decrease Hospital Costs." Research in Action: Issue 1. March 2001.

ScottYoung. The Role of Health IT in Reducing Medical Errors and Improving Healthcare Quality & Patient Safety. PowerPoint. Agency for Healthcare Research and Quality. August 2005. <a href="http://www.ehealthinitiative.org/assets/documents/Capitol\_Hill\_Briefings/Young9-22-04.PPT">http://www.ehealthinitiative.org/assets/documents/Capitol\_Hill\_Briefings/Young9-22-04.PPT</a>

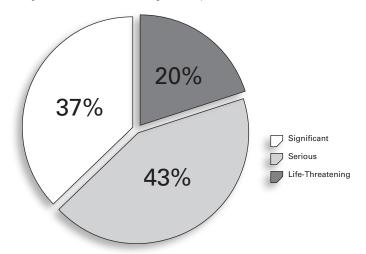
Consumers

### The financial costs

Total national costs (lost income, lost household production, disability, and healthcare costs) of preventable adverse events (medical errors resulting in injury) are estimated to be between \$17 billion and \$29 billion, of which healthcare costs represent over one-half.<sup>57</sup> According to a Markle Foundation report, the U.S. healthcare system spends \$30 billion to as much as \$293 billion annually on unnecessary paperwork.<sup>58</sup>

### Severity of Injury in Preventable Adverse Drug Events

Source: Bates, David J. Cullen, Nan Laird, et al. "Incidence of Adverse Drug Events and Potential Adverse Drug Events: Implications for Prevention." *JAMA* 274(1): 29-34 (1995).



# Financial advantages for patients

Because 90 percent of the financial benefits from health information technology goes to payers and purchasers,<sup>59</sup> financial benefits to consumers will be indirect. In particular, patients will spend less time at the doctor's office and miss fewer days at work while enjoying increased quality of care.

<sup>&</sup>lt;sup>57</sup> L. Kohn, J. Corrigan, and M. Donaldson. To Err Is Human: Building a Safer Health System. Committee of Health Care in America, Institute of Medicine. 2000.

MedStar eHealth Initiative, Verizon. "At a Tipping Point: Transforming Medicine with Health Information Technology, A Guide for Consumers." MedStar eHealth Initiative, Verizon. April 1, 2005. <a href="http://ccbh.ehealthinitiative.org/communities/community.aspx?Section=100&Category=211&Document=621">http://ccbh.ehealthinitiative.org/communities/community.aspx?Section=100&Category=211&Document=621</a>

<sup>&</sup>lt;sup>59</sup> N. Menachemi and R. Brooks. Exploring the Return on Investment Associated with Health Information Technologies, p. 36. Florida State University College of Medicine. February 2005.

#### **Families Feeling the Pinch**

In 2003, 43 million people reported financial problems related to paying medical bills.<sup>60</sup>

### **Reducing Fraud and Abuse**

In 2003, Florida Medicaid implemented a voluntary medication management and e-prescribing program for physicians caring for Medicaid patients. Since its implementation, this program has saved Florida taxpayers an average of \$700 per doctor each month. But there has been more than financial benefits: there has been a four percent drop in significant drug interactions since the program began.<sup>64</sup>

Some savings can be realized by giving providers updated and cost-effective information during the prescribing process. One e-prescribing system now in use alerts doctors to the most cost-effective treatments for patients, including generic medications, less expensive alternatives to medications in the same therapeutic class, and more appropriate drug utilization. The Center for Information Technology Leadership says this type of technology, which supports the ordering of medications, would save Americans about \$27 billion annually in medication spending. Easternative providers and the same than the same therapeutic class, and more appropriate drug utilization.

### Reduce duplication of tests

Medical tests can be painful, and sometimes they involve great risk. In addition, tests can cost a lot of time and expense: up to \$500 billion is spent on unneeded or duplicative care, which is nearly a third of our annual healthcare spending. <sup>63</sup> But under a system of connected medical data, a doctor can avoid unnecessary tests by accessing a patient's record to see if another doctor has already completed the test.

### **Dramatically reduce drug interactions**

Patients will benefit from an extra layer of protection against drugs being prescribed that, when taken together, have adverse effects. This extra protection will come from the personal health information that is provided to physicians, nurse practitioners, and others who prescribe medicine. Today, providers have no way of knowing what other healthcare providers have prescribed for a patient.

<sup>&</sup>lt;sup>60</sup> U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. Effects of Health Care Spending on the U.S. Economy 2005. August 2005. <a href="http://aspe.hhs.gov/health/costgrowth/report.pdf">http://aspe.hhs.gov/health/costgrowth/report.pdf</a>

<sup>&</sup>lt;sup>61</sup> Cap Gemini Ernst & Young. *TouchScript Medication Management System: Financial Impact Analysis on Pharmacy Risk Pools.* October 2000.

<sup>&</sup>lt;sup>62</sup> Center for InformationTechnology Leadership. The Value of Computerized Provider Order Entry in Ambulatory Settings. March 2003.

Statement of Mike Leavitt, Secretary of Department of Health and Human Services, before the Committee on the Budget, United States Senate, July 20, 2005.

<sup>&</sup>lt;sup>64</sup> Florida State. Agency for Health Care Administration. Florida Medicaid Nominated for National Award. Press release, August 3, 2004.

<sup>&</sup>lt;a href="http://www.fdhc.state.fl.us/Executive/Communications/Press\_Releases/archive/2004/08\_03\_2004.shtml">http://www.fdhc.state.fl.us/Executive/Communications/Press\_Releases/archive/2004/08\_03\_2004.shtml</a>

Most people try to do what they can to stay well—exercise and make healthy choices. When you get sick, you go to the doctor. It's an age-old formula. Healthcare providers do what they're supposed to do, patients do what they're supposed to do, and everyone hopes that the outcome will be favorable.

But much more is possible. An interoperable system of healthcare information will allow you to expand the healthcare relationship—to transform yourself from patient to partner. You can be better informed consumers, better able to make healthy choices, and better able to find treatment that reflects all your needs based on complete information, not just the information a single provider might know at any given time.

Opportunities and responsibilities usually appear together; they represent the partnership that drives progress. You as consumers must also become partners in improving your healthcare and creating needed change.

**66** Without continual growth and progress, such words as improvement, achievement, and success have no meaning. **99** 

Benjamin Franklin, Inventor and Statesman (1706 – 1790)

Consumers			
23			